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Department of Health and Social Security



Problems Associated with AIDS



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Department of Health and Social Security

Problems Associated with AIDS

Response by the Government to the
Third Report from the Social Services
Committee Session 1986–87

Presented to Parliament by the Secretary of State for Social Services
by Command of Her Majesty January 1988

LONDON

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Problems Associated
with AIDS

Report by the Government of the
Third Report from the Social Science
Committee Series 1988-9

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Response to the Third Report from the Social Services Committee (Session 1986–87) on Problems associated with Aids

Introduction

This memorandum gives the Government's observations on the Committee's 1987 report on Problems Associated with AIDS. Like the Committee's Report, this response considers the impact of HIV and AIDS and the measures taken to counter that impact in the United Kingdom and in support of the international effort.

Government Strategy on AIDS

1.1 AIDS is a new disease, the first case in the UK being seen at the end of 1981. At the time the Committee began its enquiry in November 1986 there were 548 confirmed reported cases of AIDS of which 278 had already died. By the end of May 1987, the month in which the Committee reported, the number had increased by 243 to 791. By the end of 1987 there had been a further increase of 436 to a total of 1,227 cases. As the Committee noted, this has been a rapidly changing and evolving situation.

1.2 The Government has developed a comprehensive four-part strategy to meet the growing challenge of this new disease. The four parts comprise:

- Public Education;
- Infection Control and Surveillance;
- Research; and
- Development of Health and Other Services for the care and treatment of people with HIV and AIDS.

1.3 At present there is neither a vaccine to prevent HIV infection nor a cure for AIDS. On both there is a massive worldwide programme of research. But as regards a successful vaccine, most experts agree that it will be at least five years and perhaps much longer before this can be developed and marketed. As regards a cure, the situation is more uncertain still. Indeed it is possible that, because of the way HIV enters the genetic material of body cells, a real cure, which eliminates the virus from those who have been infected, may never be found.

1.4 In the absence of pharmaceutical defences against AIDS, the most important step is to limit the spread of infection. Because AIDS is not generally infectious, but is spread by intimate contact (in the UK mainly sexual intercourse and the sharing of needles), the major weapon must be public education to persuade people to modify risky behaviour.

1.5 The Government believes that because AIDS is a new disease its strategy must be flexible and responsive. It must be carried out in close partnership with health and local authorities and the voluntary sector. The Government recognises that the voluntary sector has played a very valuable role right from the beginning and is continuing to do so. It encouraged the establishment of the National AIDS Trust which has been set up to co-ordinate and help to raise funds for the activities of those working in the voluntary sector, and also to make grants.

1.6 The Government is also convinced that a key element in carrying out its four-part strategy is international co-operation in the fight against AIDS. The world must pool its knowledge on research and on effective use of information and education programmes. For this reason, the Government is very glad to be hosting in London jointly with the World Health Organisation a Summit Conference of Ministers of Health on AIDS Information and Education.

1.7 These strategies have to be underpinned by adequate resources. The Government has allocated substantial sums to the public education campaign, to research and to international action. It welcomes the Committee's support for this. In the initial stages of the disease's development, while numbers and costs were relatively small, no specific central allocations were made for the care and treatment

services. However, as the need for care and treatment services has developed so resources have been made available — £3 million in 1986–87, £25.1 million in 1987–88 with £58.6 million planned to be made available in 1988–89.

1.8 Against this background, the Government welcomes the work which the Social Services Committee has done in preparing its report and in particular the focus which the Committee has brought to bear on the issues involved. This response broadly follows the four main sections of the Committee's Report, dealing in turn with Research, Education and Prevention, Care and Treatment, and Wider Repercussions. Each section begins with a short statement of the Government's strategy followed by replies to specific recommendations* of the Committee, which should be read in the light of the statements. Where they are clearly related the replies have been grouped together.

Research

2.1 The Medical Research Council (MRC) is responsible for co-ordinating basic and clinical research on AIDS undertaken in the public sector in the UK. It co-ordinates epidemiological, clinical and pathological research and therapeutic trials via a number of specialist committees reporting through the Council's Systems Board.

2.2 The MRC undertakes work in its own research institutes. It has also additionally funded a total of 28 special projects for general research on AIDS and immunodeficiency viruses to date at a total cost of £3.3 million. This includes up to £300,000 a year from the Health Departments for epidemiological research and for the UK Centre For Co-ordinating Epidemiological Research on AIDS. The MRC grant-in-aid has been increased by £1 million a year for the period 1987–88 to 1989–90 for general AIDS research.

2.3 In addition to this general research the MRC put forward proposals for a directed programme of research to develop a vaccine and anti-viral drugs. The Government accepted these in full in 1987 and the MRC's grant-in-aid from the Department of Education and Science has been increased by £14.5 million over three years to allow for this vital programme. Two Steering Committees reporting, through a Council Committee on AIDS, to the Council have responsibility for scientific co-ordination in the directed programme.

2.4 The lead in research on sociological and behavioural aspects of AIDS is taken by the Economic and Social Research Council (ESRC). It is developing a programme of research together with the Health Departments and the MRC.

2.5 The Health Departments take the lead on research related to the planning and provision of health care and personal social services. Their programme includes research on prevention and control of the spread of HIV infection; provision of services in hospital and the community; types and costs of services; AIDS and drug misuse, including evaluation of the needle exchange schemes for drug misusers and behavioural research. The DHSS has to date directly funded research projects which will cost over £1 million (about £400,000 has been allocated for projects in 1987–88). The Scottish Home and Health Department has to date funded research projects which will cost about £400,000. These sums exclude the contribution from the health Departments of up to £300,000 a year to the MRC for epidemiological research on AIDS (see paragraph 2.2).

2.6 The other public sector bodies pursuing research include universities, the Public Health Laboratory Service, the National Institute for Biological Standards and Control, the Central Office of Information and the Health Education Authority. Government funded organisations are working alongside the pharmaceutical industry and medical charities.

2.7 As well as research being carried out in the UK, British researchers are closely involved in international research programmes such as those developed by the European Community and by the World Health Organisation's Special Programme on AIDS.

(*Recommendation 92 sets out the Committee's view of the overall priorities in each area. A specific response is not included below as the statement of the Government's strategy sets out its position in relation to this recommendation).

2.8 The Government keeps research needs, co-ordination and expenditure under constant review, through regular meetings of the public agencies concerned chaired by the Chief Scientist of the DHSS. This is to avoid duplication of effort, to check progress and to provide a forum for the exchange of information.

Recommendation 1.

The “window of uncertainty” lasts between four weeks and four months after infection; there are isolated cases of it being even longer, up to fourteen months. So universal testing cannot be relied upon to identify all those at risk.

Recommendation 2.

We are unable to recommend the general use of anonymised screening at this stage.

Recommendation 3.

We recommend careful monitoring of the health of all babies born to mothers who are HIV positive, whether or not the children show signs of carrying the virus.

Recommendation 4.

We recommend that testing, with fully informed consent, for HIV infection be available to all ante-natal mothers as soon as possible, preceded by careful pre-test counselling by trained medical and nursing staff.

Recommendation 5.

While the prevalence of AIDS and HIV is so low in the population at large, we do not see the need for routine screening outside the context of blood donation or the donation of other body fluids, such as semen, or organs for transplantation.

Recommendation 6.

We support the RCN’s advocacy of a specific education programme in ante-natal and family planning clinics to ensure that all women are aware of the risks of HIV and pregnancy, and the availability of testing should they require it. We urge any woman who has any doubts as to her HIV status to avoid becoming pregnant until she is sure she is clear.

Recommendation 7.

We recommend that DHSS give priority to a carefully constructed programme of screening of volunteers, randomly selected in different areas of the country, to assess the prevalence of HIV.

2.9 The Government shares the Committee’s view that it is essential to achieve and maintain an adequate knowledge of the number of AIDS cases and the prevalence of HIV infection in the UK. The Report refers to the effective voluntary system that has been established by which cases of AIDS and of those found to be infected with HIV are reported in strictest confidence to the Communicable Disease Surveillance Centre or the Communicable Disease (Scotland) Unit. Further information about levels of prevalence of the infection in a selected, and so unrepresentative and healthy, sector of the population is also available from Blood Transfusion Service data. But the Government accepts that present general surveillance mechanisms need to be supplemented by detailed epidemiological studies.

2.10 The Government agrees with the Committee in rejecting compulsory mass screening. Quite apart from its practical weaknesses as an epidemiological tool, this approach would have such profound ethical and legal consequences as to rule it out

as an acceptable way of gaining information about the spread of the infection. Other approaches mentioned in the Report also raise difficult questions of principle and practice. In order to provide expert advice on these matters, a working group was set up in April 1987 under Dr Joe Smith, the Director of the Public Health Laboratory Service, to consider ways in which the surveillance of the epidemic could be improved. The initial report of the group has now been received and the Government is carefully considering its conclusions. It would be premature to comment in detail on the Committee's recommendations in this area until that consideration is completed.

2.11 The Government, in conjunction with the relevant professional bodies, will keep under review the recommendation that the HIV antibody tests should be available to all mothers as part of their ante-natal care. It has approved trial programmes of voluntary screening of pregnant women in Edinburgh and Dundee. In these two cities there is a high incidence of HIV infection among drug misusers. In considering whether or not the test should routinely be offered to all mothers account will be taken of the results of these trials as well as of the view of Dr Smith's group on the likely epidemiological value of such screening.

2.12 The Government recognises the importance of a programme of education and care that starts before pregnancy and that continues after birth. Throughout pregnancy a programme of care should be developed by those responsible for care of each mother. This programme, including diagnostic tests and counselling, should be determined after careful assessment of the needs. Where a woman may be at risk of HIV infection the Government shares the Committee's view that steps should be taken to ensure that she is fully aware of the risks of HIV infection and pregnancy. This is best achieved through individual counselling.

2.13 All newborn babies should be fully examined by a doctor experienced in their care, and continuing care as appropriate should be arranged between the hospital and community services after the mother and baby return home. This is so for all pregnancies and births, but the Government agrees with the Committee that this has particular importance where a mother has HIV infection.

2.14 The Government acknowledges that there is a need to monitor the physical condition in both the long and short term, of children born to mothers who have HIV infection. A multi-centre cohort study by research workers in Edinburgh and five other European centres is being undertaken, as part of a project within the European Community research activity on AIDS, to follow up babies born to mothers with HIV infection in areas of high prevalence of HIV among injecting drug misusers.

*The Public Health
Laboratory Service*

Recommendation 8.

AIDS has underlined the vital importance of the PHLS to the UK and we recommend that Ministers take immediate steps to resolve any uncertainties which still surround its future.

2.15 The role played by the Public Health Laboratory Service (PHLS) in response to the threat posed by AIDS is vital. The Government recognises the importance of assuring the Service's future. In recognition of the additional workload of the PHLS, particularly in HIV antibody testing and in surveillance of AIDS cases, provision of £2.5 million was included in the PHLS budget for 1987-88 which was announced in May 1987. Because of growth in that workload provision of a further £1.1 million for 1987-88 was announced in October 1987.

*Drugs, Vaccines, Basic work
& Priorities*

Recommendation 9.

We cannot expect our scientists to fulfil our requirements of them if we are not prepared to ensure that they are properly funded at the most basic level.

Recommendation 10.

We recommend that every effort should be made in the future to ensure that basic scientific research continues to be properly resourced.

Recommendation 12.

We welcome the Government's decision to fund the MRC's special programme of research towards a drug and a vaccine against AIDS.

Recommendation 14.

We agree wholeheartedly with the BMA when they said that "As far as testing vaccines are concerned, it is very important that we see AIDS as being a disease like other diseases . . . if we succumb, as scientists and doctors have succumbed in the past, to putting into use something which has not been properly tested, we may find in ten or fifteen years' time we have been misled and it does not give us the protection we thought. There is no substitute for the routine, and indeed the more important the illness, the greater the need to stick to the routine you have understood and worked out."

2.16 The Government agrees with the Committee about the importance of basic scientific research and the need to ensure that this research is properly funded. The Government continues to give funding for such research a high priority, as it has in the past. The MRC's directed programme is an important initiative and the Government welcomes the Committee's support for its decision to fund this work.

2.17 The Government agrees too with the views put forward to the Committee in respect of testing vaccines: it is important that the normal thorough procedures are followed. HIV vaccines must be properly tested following the standards of quality, safety and efficacy applied to the search for other vaccines.

Recommendation 20.

There is still much to be learned about the basic function of the virus, the exact mode of its transmission, including to babies and its effect on the immune and nervous systems. The need for further epidemiological study, including study of the natural history of HIV infection, has been put to us time and again as one, if not the most pressing priority next to a vaccine. To this list can be added clinical research into the opportunistic infections which attack patients with AIDS, a more sensitive antigen test, and a means of detecting HIV2 and evolving viral strains.

2.18 The Government shares the Committee's view that more work is needed on the basic function of the virus, the modes of its transmission and its effect on the immune and nervous systems. The MRC and the Health Departments have already set up a substantial amount of epidemiological research which will, over the next few years, add to our understanding of how the infection is spread. The MRC's directed programme will include basic research on the virus and its effect on the immune system. Some studies of the effect of HIV on the nervous system have been supported by the MRC and more are planned; the same is true for clinical research on opportunistic infections. The Wellcome Foundation is developing an antibody test for HIV2.

2.19 The UK, however, is only one country out of many doing research into AIDS and international research is also important in securing more knowledge to facilitate the prevention, cure and control of AIDS and other diseases. The Government carefully monitors international developments in all respects of AIDS research. In addition to Government funded work at home, UK scientists also collaborate with their colleagues in other countries in less formal ways.

Recommendation 21.

We recommend that sociological research into AIDS be given the funding and the priority it deserves.

2.20 The Government shares the view of the Committee that sociological, including behavioural, research into AIDS should be undertaken as a priority. Funds have

already been allocated to existing Economic and Social Research Council (ESRC) Unit programmes on behavioural research to allow them to cover HIV-related problems. The ESRC is now developing a separate programme of research in discussion with the DHSS and the MRC and is represented at the DHSS Chief Scientist's Meeting which monitors AIDS research (see paragraph 2.8). For a three-year period from November 1987 the ESRC is devoting almost £500,000 a year to sociological and related research on AIDS.

Recommendation 11.

We recommend that the Secretary of State for Education take a much firmer line in ensuring that monies allocated from his budget for clinical academic research are not abrogated for providing clinical care by default. Everything we have said before regarding basic scientific research applies doubly so to basic clinical research. At present the NHS is relying on clinical academics. To fail to make full and proper recognition of their needs is not just stifling the present, it is mortgaging the future. We look to the Whitelaw Committee, collectively and individually, to safeguard this most valuable resource by ensuring it has the resources it needs.

2.21 The Government makes resources available for clinical research through the Secretary of State for Education in two ways: through the MRC and through the grants to universities made on the advice of the University Grants Committee (UGC). The UGC in its grant allocations, takes explicit account of the quality of research in individual institutions, but does not earmark funds for research. The UGC has recognised that, in the period since 1981, numbers of clinical academic staff wholly funded by the universities have fallen disproportionately by comparison with other academic staff, and in its most recent allocations has advised universities that that is not its intention. One result may have been pressure on clinical academics' time. But clinical academics have a standing commitment to teaching, research and patient care, recognised in the system of mutual uncosted assistance ('knock for knock') by which the medical schools are funded, and the service commitment of academic staff is a necessary and valued part of their function.

2.22 AIDS has increased the pressure on clinical academics. The Government has sought to relieve this by additional funding for research and by additional funding for the health authorities mainly involved in the treatment of people with AIDS (paragraphs 2.5 and 4.7).

Recommendation 13.

We recommend that it become standard practice for every failed applicant for research funding to receive a written critique of his proposal and that channels of consultation are established in order to facilitate the redrafting.

2.23 It is already the practice to help researchers who put forward research proposals which appear capable of being turned into viable and valid projects (eg where the basic issues of the study are valid but the methodology is inadequately developed). To this extent the Committee's proposal is already in operation. But there are always likely to be more applications than research monies available and it would not seem worthwhile as a general rule to adopt this approach with proposals that clearly show no promise, although there may be cases in which discussion is needed to enable a sound decision to be made about whether or not to pursue proposals further.

International aspects

2.24 The Government shares the Committee's view of the importance of the international dimension of the fight against AIDS. The World Health Organisation (WHO) have received reports of people with AIDS in over 120 countries and they currently estimate that throughout the world there may be between five and ten million people with HIV infection. The spread of AIDS and HIV infection thus has to be regarded as a global problem which requires a global response if it is to be overcome.

2.25 Great emphasis is therefore placed upon the need for effective measures of international co-operation in the face of this universal threat. The full and continuing exchange of information, expertise and experience between countries is vital. There is much that the UK with its considerable traditions in medicine and research and its expertise in health education can contribute. But equally there is a great deal that can be learnt from how other countries are tackling the problem.

2.26 It is also essential that international action is taken in a co-ordinated manner so that priorities are established and programmes of assistance and research are carefully planned and properly carried through. Without such co-ordination there is a danger that there will be duplication of effort in some fields and a concomitant lack of action in others. The available resources and expertise would thus not be used in the most efficient and effective way.

2.27 In this respect the WHO has a pivotal role. The Government has continued to maintain close links with the WHO's Special Programme on AIDS. By mid-September 1987, US\$44 million had been pledged to the Programme, including the £3.25 million (approximately US\$5.3 million) which the Government has contributed from the Aid Programme.

2.28 The Government's support for WHO's Special Programme on AIDS was stressed by the former Secretary of State for Social Services, Mr Norman Fowler, when he addressed the World Health Assembly in Geneva in May 1987. This message was reinforced when the present Secretary of State for Social Services, Mr John Moore, addressed the United Nations General Assembly in October 1987. The UK and the WHO are jointly organising a World Summit of Ministers of Health on Programmes for AIDS Prevention. This meeting will take place in London on 26-28 January 1988, and its main objective will be to provide world Health Ministers and their senior policy makers with a forum for considering the prevention and control of AIDS, with particular emphasis on the strategies needed in public information and education.

2.29 In addition to support for the WHO Special Programme, the Government has played a leading role in the development of measures in response to AIDS by the European Community (EC). It was at the UK's initiative that AIDS was discussed at the meeting of the European Council in London in December 1986. Following that meeting the Government supported the Conclusions of EC Health Ministers of 15 May 1987 on AIDS and the establishment of a working party to develop a common strategy for preventive action and exchange of information; the EC Development Council has agreed a programme for assisting developing countries, and a programme of AIDS research is being implemented.

Recommendation 15.

We are pleased that the Government has taken such a supportive stance towards the WHO's Special Programme on AIDS. We trust that it will be maintained in the future and that other countries will take a similarly generous attitude.

2.30 The WHO Special Programme has achieved a great deal since its establishment in February 1986. By 1 November 1987, it had made assessment visits, the first stage in its collaboration with Governments, to 93 member states; another 34 were scheduled for the end of 1987. These missions have led to the preparation of over 50 short-term (6-12 months) national AIDS plans, the second stage of collaboration, which will be funded by the Special Programme. The Programme is now collaborating with 86 member states in the preparation of comprehensive three to five-year plans, the third stage of collaboration, for the prevention and control of AIDS. The question of the Government's future support for the Programme will be considered against the Programme's needs and existing demands on the Aid Programme.

Recommendation 16.

We recommend that the ODA ensure that "the cutting edge of the United Kingdom's research effort in tropical medicine" remains sharp.

2.31 The Overseas Development Administration (ODA) is only one source of research funds for tropical medicine. The ODA has consistently supported tropical research in this country through the joint MRC/ODA Tropical Medicine Research Board (in 1986–87 the total expenditure on this work was £7.2 million which included a contribution from the ODA of £1.56 million) and by providing support for the Liverpool and London Schools of Tropical Medicine. In 1986–87 the ODA provided more than £1.25 million to the two Schools for salaries and related costs.

Recommendation 17.

In addition to the funding of research, Africa urgently requires significant additional resources from the developed world, including the UK via the ODA's health and population programme to install screening and testing facilities, and to ensure adequate supplies of reusable, sterilisable equipment.

2.32 Through the ODA the Government provides about £38 million a year in health and population assistance from the Aid Programme. The broad objective of this expenditure is to strengthen health services in developing countries. In doing so, it will also help countries deal with AIDS. The ODA has also participated in bilateral donor meetings in Uganda, Kenya and Tanzania, called jointly by the recipient Government and the WHO, to discuss bilateral funding for the medium-term (five-year) AIDS plans. These plans include specific provision for screening and testing facilities and re-usable, sterilisable equipment. British bilateral assistance from the Aid Programme will be made available to all three countries to help them implement their plans. The Government is also supporting research into the longer-term economic and social implications of AIDS in the developing world, and has provided £1.6 million to the International Planned Parenthood Federation to help it develop public education materials.

Recommendation 18.

We recommend that the MRC continue to give high priority to funding research in Africa, not only of the epidemiology and virology of HIV infection, but also of the likely accompanying epidemic of opportunistic infections such as tuberculosis and cryptosporidiosis.

Recommendation 19.

All agencies involved in research in Africa must take responsibility for their own ethical practices and for protecting those they work with against the unethical practices of others .

2.33 Proposals for research in Africa are considered by a joint Board of the MRC and the ODA; the Tropical Medicine Research Board. Following requests for assistance from the Gambia and Uganda, the Board is encouraging the development of two major proposals for research in these two countries. Proposals for research in other parts of Africa are being considered. The extent to which the Board will be able to support such work will depend on the funds which the MRC and the ODA are able to make available in view of their other commitments and priorities.

2.34 The Government shares the Committee's view that all agencies involved in research in that continent must take responsibility for their own ethical practices and for protecting those they work with against the unethical practices of others. Research on AIDS in developing countries is vital but sensitive. The Government believes it cannot be carried out without local approval and co-operation. Ethical standards must be observed. In some countries ethical committees need strengthening. The Government believes that the WHO Special Programme on AIDS has a particular responsibility to help in this area. The Programme is already working on guidelines for vaccine and drug trials in developing countries.

Education and Prevention

3.1 The Government has a public health duty to provide health education about AIDS and HIV. As the Committee acknowledges in paragraph 53 of its Report, efforts must be made to educate the public so that they understand how the virus is transmitted, what activities carry the risks, and how such risks can be avoided. In the absence of a vaccine or cure, education is the chief way in which the spread of infection can be curbed.

3.2 The public education campaign has been based on three broad aims:

- to inform people about the facts concerning AIDS and HIV infection and its transmission;
- to inform how the risk of transmission of HIV can be avoided or reduced; and
- to seek to change attitudes and reduce the amount of risky behaviour.

3.3 The campaign has sought to target both the general population and specific groups with information relevant to their needs and in language they understand. A key element in the development of the campaign is a continuing process of monitoring, piloting and evaluation.

3.4 The campaign has delivered three key messages:

- reduce the number of your sexual partners — preferably to one faithful partner;
- if you are not sure of your partner, use a condom; and
- don't take illicit drugs, if you do and can't stop then don't inject, and never share equipment.

3.5 In the 1986–87 financial year some £8 million was spent with the objective of informing all sections of society about the disease, how it is spread, how it is not spread and how individuals can protect themselves and others. Market research suggests that this money has been well and effectively spent. Most of this sum falls within the £20 million that the Government has committed for spending on the public education campaign and evaluation of its effectiveness. The Government accepts the need to commit resources to sustain the high levels of knowledge achieved and to achieve attitudinal and behavioural change among both the general heterosexual population and among those groups at greatest risk. Research will be needed to help formulate messages which will be likely to achieve these objectives and to measure their effectiveness.

3.6 The Government takes every appropriate opportunity to share views and experience of public education activities with other Governments. Exchanging information materials, for example, has often proved mutually useful and beneficial.

Recommendation 22

We recommend that the public information campaign become more specific, but we believe that a general campaign of information and education should continue.

Recommendation 24

We repeat our belief in the need for an education campaign focused at specific groups, but it should attempt to speak to each section of society in terms it will understand and take notice of, rather than directing attention towards distinctly labelled, but loosely defined categories. This calls for a number of smaller, specifically-directed campaigns, which should be no less intensive than the initial mass-media campaign.

Recommendation 25

The alienation of any sub-group from the rest of society, whether by their own intent or through the attitudes of others, will undermine the public health, since they may not then feel any responsibility to act for the general good, especially in preventing the spread of infection. We recommend that likely reactions are taken into consideration when planning the targeted campaigns.

Recommendation 26

We recommend that if the Government is not prepared to be as explicit as may be necessary in the information targeted at specific groups (and we understand why this might be so), it should devolve the work those who are.

3.7 The first phase of the campaign was intended to raise the general level of public awareness about AIDS and to increase general knowledge of the ways in which HIV infection is and is not transmitted. Market research commissioned to evaluate the campaign suggests that it has been largely successful in meeting these objectives. For the future, the strategy will be to maintain and reinforce levels of knowledge about AIDS amongst the general population and to translate this knowledge into action by encouraging attitudinal and behavioural change amongst those whose behaviour puts them most at risk. This will require material that is more precisely targeted. In September 1987 the Government launched the second stage of the campaign which focuses on the need to warn young people against injecting drugs because of the risk of infection through shared needles and syringes. At the same time, the third phase of the drug prevention campaign was launched to complement the anti-injecting message. This stage of the AIDS campaign was not actively promoted in Northern Ireland in view of the very low incidence of injecting drug misuse in the Province.

3.8 Further stages of the campaign will be carried forward by the Health Education Authority, in close collaboration with the Scottish Health Education Group, the Welsh Health Promotion Authority and relevant Government Departments, and in the light of research. In addition, the encouragement of local education initiatives is envisaged, involving the participation of both statutory and voluntary bodies. Such initiatives will take account of the specific needs of local communities.

3.9 The Committee's view of the need to ensure that AIDS information is presented in ways acceptable and relevant to the target audience is shared by the Government, particularly where the objective is to effect behavioural change. Any reinforcement of feelings of alienation or stigma could lessen the impact of the campaign and, in this respect, researching and piloting of material to be used are most important.

3.10 The Government shares the Committee's view that educational material is often best put across by bodies active in particular fields, eg among the homosexual community or representing disabled or sensorily impaired people, or those from ethnic minority communities. Their advice in presenting and putting out messages about AIDS to these groups is greatly valued.

Recommendation 23

We further recommend that the general campaign should be geared more towards those who do not read pamphlets or newspapers.

3.11 The Government accepts the need to ensure that all sections of the population have access to information about AIDS in an appropriate form. Funding has been provided for visual and audio material for the visually and aurally impaired, and material for people with reading and learning difficulties will be produced. Action has also been taken to produce material relevant and acceptable to ethnic minorities, including the establishment of a dial and listen service in the main languages of the Indian sub-continent and Cantonese. This service came in to operation in November 1987. The continued funding of the National AIDS Helpline provides telephone access to information and advice.

Recommendation 31

We conclude that the wisest approach is to advocate celibacy before marriage and fidelity within it as the ideal, but to accept that people may find this hard to achieve.

Recommendation 32

“Safe sex” is now an inescapable personal responsibility.

3.12 The Government recognises that AIDS raises complex moral, social and ethical questions. Celibacy before marriage and fidelity within it, as the Committee says, is the best way of avoiding the risk of HIV infection by sexual transmission. A key message of the campaign has been to advise people to cut down on the number of their sexual partners, preferably to one faithful partner: it has warned that having multiple sexual partners, and changes of sexual partner, increase the risk of catching or transmitting HIV infection. However, the Government also agrees with the Committee that this advice may not be acceptable to all groups and particularly to some of those who are most at risk. For this reason, the campaign has also emphasised that individuals should seek to reduce the risk to themselves and others by appropriate precautions and by the avoidance of high-risk practices.

3.13 The Government notes the Committee's endorsement of public advertising of condoms. Television advertisement of branded products is now taking place within guidelines drawn up by the Independent Broadcasting Authority.

Recommendation 30

We recommend that DHSS examine the contribution which information technology can make to the dissemination of accurate information about HIV and AIDS.

3.14 The Government recognises that information technology could help in the dissemination of accurate information about AIDS. AIDS is one of a number of subject areas for which some form of electronic distribution might be useful. The DHSS is willing to consider giving priority within its existing information technology research and development funds for work in this area if suitable proposals are forthcoming.

Recommendation 47

Professor Adler said that "it seems to me that we have a golden opportunity here to get preventative medicine right for once in the United Kingdom." It seems to us that it is an opportunity we can little afford to squander. We recommend a far higher level of input of behavioural, psychological and sociological research in the formulation and assessment of the publicity campaign.

3.15 The Government agrees with the importance of behavioural psychological and sociological research inputs. The first stage of the campaign concentrated on creating a high level of awareness of the basic facts about AIDS amongst the general population. The campaign has been closely monitored by independent market research and the results of this were published in September 1987. The campaign now needs to address the more complex problem of changing attitudes and ultimately personal behaviour. Extensive research was used to establish the approach most likely to achieve this objective in the development of the latest stage of the campaign targeted at drug misusers. Consideration is being given to the development of other measures of behavioural change which might be developed in tandem with continued market research amongst the target audiences. The Health Education Authority will also be undertaking research.

Voluntary Sector

Recommendation 27

We recommend that the work of the Terrence Higgins Trust should be supported by the Government in terms commensurate to its value in the fight against AIDS and that the DHSS should carefully monitor this work.

Recommendation 28

The voluntary sector has made a major contribution towards educating the public about AIDS; we hope that they will work with the statutory sector to build on what they have already achieved.

Recommendation 29

We recommend that the Government and other statutory agencies commit themselves to long-term funding for helplines throughout the country.

3.16 The Government fully acknowledges the importance of the voluntary sector in the fight against AIDS. DHSS grants in 1986–87 to voluntary bodies in the AIDS field amounted to just over £¼ million. Already in 1987–88 over £1½ million has been committed under section 64 of the Health Services and Public Health Act 1968, as well as central financial support for the National AIDS Helpline. This increase in Government spending reflects the view that voluntary sector bodies, like the Terrence Higgins Trust, have a vital role to play in complementing the efforts of statutory agencies in a whole range of fields including education, information, counselling and care and support of people with AIDS or HIV infection. The Government shares the Committee's hope that voluntary bodies will work closely with the statutory agencies to build on what has been achieved. To promote a co-ordinated approach guidance has been given to health authorities about the need to devise plans for the provision of AIDS-related services in conjunction with local authorities and the voluntary sector.

3.17 The Government greatly appreciates the work of the Terrence Higgins Trust. In August 1987 it made the Trust a grant of £300,000 for 1987–88. This is nearly a three-fold increase over the previous year's grant. It reflects the important work the Trust carries out in providing advice and information on a wide scale, and in supporting and counselling those with AIDS or HIV infection. The Trust has grown remarkably in just a few years. The size of the Government grant is a measure both of that achievement and of the importance of the work the Trust undertakes.

3.18 Work carried out by the Scottish AIDS Monitor in providing a telephone referral system, counselling and support is much appreciated too. The Government has substantially increased the Monitor's grant to £46,400 for 1987–88 in recognition of the valuable service provided to the community.

3.19 The Government shares the Committee's view that helplines play a valuable role. It has supported a 24 hour free telephone service for people wanting to talk in confidence with a trained advisor. The National AIDS Helpline has been enhanced by the recruitment of advisors from the ethnic minority communities and by the provision of in-service training to help its staff deal with enquiries about the drug-related risks of infection. The Helpline will continue to receive central financial support until at least the end of this financial year when its effectiveness in meeting needs will be evaluated and its future role considered in the light of future needs and this evaluation. It is for health authorities, local authorities and voluntary bodies, working together, to determine the needs for locally based AIDS helplines.

National AIDS Trust

Recommendation 90

We welcome the establishment of the National AIDS Trust, and wish it well. We trust, however, that its establishment does not mean that the Government sees the voluntary sector as the main focus for dealing with AIDS.

Recommendation 72

We recommend that the new National AIDS Trust encourage housing associations and charities to provide accommodation for those made homeless as a consequence of HIV.

3.20 The Government agrees with the Committee that voluntary effort cannot replace the role of statutory services. The intention is rather that the two should work together in providing an effective service in dealing with HIV infection and AIDS. The Government has provided financial support for the National AIDS Trust (NAT) which has been set up to promote and co-ordinate voluntary effort on AIDS, and to help fund-raise, and also to make grants. It is envisaged that the NAT will be seeking to promote links between voluntary and statutory bodies both at national and local level.

3.21 The Committee's Recommendation concerning accommodation for people made homeless as a consequence of HIV has been referred to the NAT, so that it can take it into account in the formulation of its general strategy and priorities.

Drug Misusers

Recommendation 33

None of our evidence provides much advice on how to deal with the problem of AIDS and HIV infection in the drug abusing population. It is the most difficult feature of the whole AIDS problem.

3.22 The Government agrees with the Committee that AIDS and HIV infection and the injecting drug misusing population is a very difficult and important issue. Government action to reach this group includes a new stage of both the AIDS and the drug prevention campaigns which together seek to:

- dissuade young people at risk from misusing drugs;
- dissuade drug misusers from injecting; and
- dissuade injecting drug misusers from sharing equipment.

3.23 Other action taken includes:

- more cash to help services reach more drug misusers and provide health education;
- trial needle exchange schemes which are being carefully monitored and evaluated; and
- an examination by the Advisory Council on the Misuse of Drugs of the implications of AIDS for drug misuse services. This includes urgent consideration of measures which can be taken to help combat the spread of HIV infection on which the Advisory Council were asked to report by the end of 1987.

3.24 The work of the Advisory Council and the evaluation of the trial needle exchange schemes should bring insights into needle sharing and ways of reaching drug misusers and educating them away from sharing. The Government is currently funding a research project looking at help seeking amongst drug misusers, and recently funded a study of the experiences that heroin misusers in the Wirral have of medical and other treatment. Consideration will be given to any other work which may point the way to practical solutions.

Recommendation 34

We recommend that the needle and syringe exchange scheme be extended to other areas of the UK only if and when there is sufficient evidence that such schemes can be effective in restricting the spread of AIDS, accompanied by strong and sufficient education on "safe drug misuse". In addition, we see no reason why needles and syringes should not be on sale in chemists' shops accompanied by suitable health education material.

3.25 The Government agrees with the Committee that the possible extension of needle exchange schemes should be considered in the light of the evaluation of the trial projects. As regards the sale of needles and syringes in chemists' shops, accompanied by suitable health education material, some retail pharmacists currently sell injecting equipment to drug misusers, and of these a proportion already provide health education material. Specialist counselling and disposal facilities, however, are not generally provided. The Government will consider with syringe manufacturers and the pharmacists' professional bodies what steps can be taken to ensure that health education material is always provided when syringes are sold to drug misusers. Further consideration will be given to the arrangements for supply of sterile equipment in the light of the evaluation of the needle exchange schemes.

Recommendation 35

We wish in particular to draw attention to recommendations 5 and 6 of the McClelland Report. We recommend that the government commit itself to providing long-term support for voluntary drug advice agencies.

3.26 The Government considers that effective arrangements exist for the funding of voluntary organisations providing local services. Health and local authorities have been given the responsibility for funding local services because they are best placed to assess competing local priorities and the needs of individual services. Voluntary organisations contribute towards the provision of local services and the DHSS drugs initiative was a pump-priming measure to encourage the development of such services. £17.3 million has now been allocated to 188 statutory and voluntary sector projects. As the Committee has recognised, this initiative allowed many excellent projects to get off the ground and the vast majority of the voluntary sector projects whose initial funding has ceased has secured future funding. An extra £5 million a year was made available to health authorities in England from 1986–87 specifically for the development of drug misuse services, and authorities are expected to apply a reasonable proportion of this money to voluntary sector projects. A further £1 million has been made available in 1987–88 to enable agencies to reach more drug misusers and to provide more counselling on AIDS. Health authorities have also been asked to give priority to the development of services for drug misusers within existing resources, including those available from cost improvement programmes. In relation to local authority services the Rate Support Grant Settlement for 1987–88 included £5 million provision in respect of extra services required for AIDS and drug misusers. In Scotland, Circular NHS 1987 (GEN)6 issued in February 1987 provides that projects funded centrally by the Scottish Home and Health Department until March 1987, and new projects funded under the additional £300,000 a year made available from 1987–88, may be supported for up to seven years from 1987–88. The extra money which has now been allocated to Greater Glasgow, Lothian and Tayside Health Boards means that over £1 million a year has been set aside in the health programmes in Scotland specifically for the support of services for drug misusers, including projects run by voluntary organisations. In Wales since 1985–86 £1.064 million has been allocated to district health authorities and voluntary bodies for the development of services for drug misusers. Funding is on a recurrent basis for the duration of projects, subject to review after three years that the services continue to be needed and are effective. Recently, the Welsh Office received bids from district health authorities for funds to support AIDS prevention activities and funds (£33,500 a year) have been made available specifically for the counselling of drug misusers.

Recommendation 36

We have to accept that so far the anti-drugs campaign has failed conspicuously in many quarters of society.

3.27 The Government does not accept that the anti-drugs campaign has failed. The target audience for the public information campaign was young people at risk of misusing drugs and not those who already misuse drugs. At the time of an alarming increase in heroin misuse among young people, the purpose of the national advertising campaign was not so much to persuade existing misusers to give up drugs as to reduce the number of younger people prepared to embark on drug misuse. The campaign sought to do this by informing young people about the true consequences of heroin misuse and by helping reinforce their resistance to experimentation.; The Government considers that the campaign has achieved these objectives.

3.28 The effects of the advertising campaign are being independently evaluated. This evaluation involves the regular monitoring of the knowledge and attitudes of young people towards drugs in general and heroin in particular. It has shown so far that the campaign has been very widely noticed and that young people's attitudes have hardened against drugs over the duration of the campaign. Attitudinal changes include a reduction in the number of young people who see heroin as glamorous, an increase in the awareness of the physical and social ill effects of heroin misuse and a reduction in willingness to experiment with the drug. The impact of the campaign has been broadly maintained and resistance to heroin remains considerably higher than before the campaign began. Awareness of the social consequences of heroin misuse increased significantly in the second year of the campaign and there was sustained awareness of the health risks. The Government believes that overall the two year campaign has had a sustained and valuable impact: it has alerted young people to the dangers of misusing drugs and moved them away from likely trial. The evaluation of the drug campaign in Scotland suggests that it has also made a valuable contribution to the overall response by the Government and other agencies in tackling the drugs problem.

Recommendation 37

The anti-drugs campaign must be redirected to warn everyone, but especially the young, that drugs will not only “screw you up” eventually, but that the act of taking them intravenously at all may “screw you up” permanently.

Recommendation 38

The warnings against ever experimenting with drugs must now have a new and greater urgency.

3.29 The Government believes that warnings against experimenting with drugs, especially for the young and for those who may start to use drugs by injection, should receive even greater emphasis in the light of AIDS and HIV infection. The education and information campaign against drug misuse has been effective in raising the level of young peoples' awareness of the dangers of drug and particularly heroin misuse. However, injecting drug misusers' vulnerability to HIV infection through sharing injecting equipment clearly introduces a new and urgent dimension to the problem, which is being addressed in the most recent stages of the AIDS and drug prevention campaigns and which must be taken into account in the Government's plans for further national publicity against drug misuse.

3.30 At the beginning of September 1987 a new phase of the campaign with two main elements was therefore launched. The first comprises hard-hitting preventive messages aimed at all young people but particularly those at risk of experimenting with drugs and at casual misusers. The second addresses existing drug misusers to dissuade them from ever injecting and explains the dangers of sharing equipment. The material has been tested to ensure that the anti-injecting element of the campaign complements and underlines the preventive element. The anti-injecting element of the campaign extends to Scotland and plans for the further development of the drug prevention campaign in Scotland are under consideration. As noted above (paragraph 3.7) the anti-injecting and the drug prevention campaigns, however, were not extended to Northern Ireland.

Recommendation 39

The potential of prostitutes as health educators of their clients should not be forgotten. Ultimately, we have to accept the BMA's view that anyone going to a prostitute does so of their own free will, and may therefore be co-operating in an act which puts themselves at risk: “If you do put yourself at risk, you should share in the responsibility for the disease that you may catch”.

3.31 The Government shares the Committee's concern that prostitution potentially presents a risk for the spread of infection in this country. There is a lack of reliable information in this area, which makes it particularly difficult to establish with any accuracy the form and extent of the risk; nor is it clear what scope exists for securing further information. Nonetheless the Government considers that it is essential to seek to minimise any potential transmission of infection by this route. In order to do so it is important that both prostitutes and their clients are made fully aware of the risks they run. The Government endorses the Committee's praise for the work being carried out at St Mary's genito-urinary medicine (GUM) clinic and at other centres to provide care and health education for prostitutes.

3.32 It is not considered that there is much scope for pursuing in practice the Committee's suggestion that prostitutes may themselves have a role as health educators of their clients in any formal sense, particularly given the very heterogeneous nature of prostitution in this country. But it is clearly vital that prostitutes are aware of the risk of infection they and their clients face and it is therefore doubly important that prostitutes are informed about how HIV is transmitted and how to reduce the risks of transmission. The possible ways of building upon what is currently being done locally and the development of further avenues for providing information and advice, for example through the continuing education campaign, are being explored.

Recommendation 40

We reiterate our conviction that prisoners who are seriously ill should normally be in hospital, not in prison, whatever their complaint. Plans for isolation units in prison obscure the very real problems HIV infection and AIDS represent for the Prison Service.

Recommendation 41

If the Departments responsible for the prisons of this country have grasped the full implications that AIDS and HIV will have for the prison system, they have yet to show it. They must develop a much more responsive and responsible attitude if they are to meet this problem. In order to prevent the spread of HIV infection in prisons, it may be that the government will need to consider at some stage permitting the prescribing of methadone to addicts in prison.

3.33 The Home Office and other Departments responsible for prisons are deeply aware of the problems posed by AIDS. In fact, they have initiated and maintained the vigorous education effort needed to avert irresponsible and irrational reactions among staff and inmates. Further guidance will be issued as and when additional information becomes available. Prison Department policy takes account of the link between injecting drug abuse and the spread of HIV. Very considerable efforts are made to control the introduction of drugs into prison establishments, and to identify drug addicts and withdraw them from their drug addiction. The prescription of methadone as part of a course of medical withdrawal of a drug addict from his drug of addiction would be a matter for an individual medical judgement by the doctor for his patient, and not a matter for administrative direction.

3.34 Prison Medical Services are not staffed or equipped to provide a complete health service. The policy will continue to be to transfer out to suitable NHS specialist attention all those inmate patients whose condition necessitates it in the professional judgement of the medical staff concerned. There are no plans for isolation units in the generally understood sense of that term in the prison system. (Potential adverse reactions from staff and other inmates, which would be the only pressures for isolation, are yielding to intensive education programmes.) The only conversion of prison hospital accommodation currently envisaged is at Brixton, where a care and support facility is planned. This will cater, among other patients, for any prisoner suffering from AIDS who may have been transferred to an NHS specialist unit for treatment during an acute episode and then, on the successful conclusion of that treatment, is returned to the prison system as he is still serving a custodial sentence. Such a person in the community at large would have been sent home. In these circumstances, his immune system will be damaged and he will require support, care and protection from the rest of the community from whom he might pick up infections to which he had little resistance.

Recommendation 42

With the advent of AIDS, “all we said about monogamy and everything else makes sense in the biological context”. Having provided this “moral backbone”, we also agree with Professor Kennedy, the BMA and the Church of England’s Board of Social Responsibility that realities of life (however unpalatable) should be accepted, and the contingencies of safe sex should be included in sex education in schools.

Recommendation 43

Whatever policy governing bodies adopt towards sex education, we recommend that DES issue forceful guidance to schools on the risk of AIDS associated with drug abuse and on necessary immediate amendments to education about drug abuse.

Recommendation 45

We recommend that all children of secondary school age receive formal health education about AIDS and HIV in relation to sexual behaviour and drug education; that primary teachers should be adequately prepared to answer children's questions on the subject at an earlier age; and that a variety of teaching materials, including videos, be developed and distributed to schools as a matter of urgency.

3.35 Under the provisions of the Education (No 2) Act 1986 it is now the responsibility of individual governing bodies in England and Wales to decide whether and, if so, how sex education is provided in schools. The Government trusts that, in determining their policy in this area, governors will take note of the Committee's recommendations, within the overall statutory framework for sex education.

3.36 A primary aim of any programme of sex education should be to encourage responsible sexual attitudes and behaviour amongst young people. Circulars from the Welsh Office and the Department of Education and Science (DES) on sex education have recently been issued to all education authorities and maintained schools in England and Wales and to other interested bodies. The Circulars emphasise the need for a moral framework for sex education and for due regard to be given to the value of family life (as required by section 46 of the 1986 Act) with pupils being encouraged to consider the importance of self-restraint and recognise the risks of casual and promiscuous sexual behaviour.

3.37 As emphasised in the DES evidence to the Committee, sex education should not assume that pupils are sexually active or in any way advocate or encourage sexual experimentation on their part. In relation to AIDS, pupils need to be informed not only of how the virus is transmitted but also of how infection can be avoided. In this context, schools will wish to discuss the place of abstinence and self-restraint, fidelity within marriage and the need for a careful choice of partners.

3.38 The DES and the Welsh Office are providing every secondary school with pupils in the 14 to 16 age-range with a video resource package about AIDS for use with pupils at the discretion of governors, intended to serve both as a core and catalyst for schools' provision in this difficult area. The Users' Guide which accompany the video offers guidance on ways in which AIDS can be presented in a variety of teaching contexts. It stresses the need for pupils to be reminded of their responsibilities and of the value and virtues of family life. Consideration will be given to what further steps might be taken in this area in the light of reactions to the package and trends and developments in AIDS education.

3.39 The Government made clear in its evidence to the Committee that teachers including those in primary schools, should, in general, be prepared to respond to any questions raised by younger pupils about AIDS. Particular skill and sensitivity is clearly needed in handling such a difficult subject at this level. Equally, however, it would be wrong for teachers to refuse to respond to pupils' concerns and thus risk leaving them confused and unnecessarily anxious. Copies of the Government's factual booklet "AIDS: Some Questions and Answers" were sent to all primary and secondary teachers so that they are able to answer pupils' questions. The Government is considering whether further guidance to teachers at this level is needed, and if so, the form it might take, subject to availability of the necessary resources.

3.40 The Government accepts that drugs education in schools must now refer to the risks of HIV infection through the sharing of equipment for injecting drug misuse. Equally, teaching about AIDS must not overlook the drugs dimension. The 1985 DES and Welsh Office booklet "Drug Misuse and the Young" drew attention to the general health risks from non-sterile injecting practices but did not refer specifically to HIV infection. However, there are specific references to AIDS in the curriculum package "Drug Wise" funded by the Government and prepared by the Health Education Council in association with other agencies: this has been made available to all education authorities in England and Wales. "AIDS: Some Questions and Answers" also refers to the risks associated with drug misuse.

3.41 The DES/Welsh Office video package is being drawn to the attention of the local education authority co-ordinators for drugs education, whose appointment is funded by DES through Education Support Grants. This will ensure that they are fully and accurately informed of the facts about AIDS and are thus able to promote and support activities at local level intended to convey the essential message to young people who are at risk. If there is evidence that schools require further help in tackling the drugs aspects of AIDS, the Government will seek ways of providing it.

3.42 In Scotland, there are no school governing bodies, and decisions about the detailed content of a school's programme of sex education rest with education authorities and head teachers although the new school boards which the Government proposes to establish will have the right to be consulted on all curricular matters. The Scottish Education Department (SED) has made it clear in a note of guidance to all teachers in educational establishments that in the longer term there is a need to include structured teaching relevant to AIDS in the curriculum of all pupils. Many education authorities in Scotland have already adopted coherent health and sex education programmes within which such teaching can be accommodated, but for those which have not, important initiatives have been taken at national level to provide a health and sex education framework which can readily be adapted by schools, whatever their circumstances. In particular, the Consultative Committee on the Curriculum (CCC) and the Scottish Health Education Group (SHEG) are collaborating on a project to provide guidelines on health education for the 10 to 14 age group. In addition, Strathclyde Regional Council have set up a curricular project with a significant contribution of funds from the SED. Its aims are, firstly, to develop a nationally acceptable framework for health and sex education from pre-five to 16 taking into account the guidelines developed by the CCC/SHEG working group, and secondly to devise a package of curricular materials on AIDS for use within such a framework. The SED has arranged for the project team to receive guidance from a national consultative group representing the interests of the Convention of Scottish Local Authorities, parents, the NHS, the main churches and the teaching profession.

3.43 The remit of the project team stresses the importance of ensuring that each stage of a health and sex education framework builds on pupils' previous experience and knowledge and promotes positive attitudes. It also invites the project team, in preparing curricular materials, to take into account parents' interests. The materials resulting from the project are expected to deal with various ways of minimising the risk of HIV infection or other diseases arising from sexual behaviour. They will do so in a way which is consistent with stressing the value of family life and the many dangers involved in casual or promiscuous sex.

3.44 The CCC and Strathclyde Regional Council recently collaborated on a project "Drugwise 12-14" to develop a package of curricular materials, including video, for this age group dealing with the dangers of drug abuse. This package, which is now available throughout Scotland, provides for teachers in discussion with pupils to make appropriate references to the dangers of HIV infection arising from non-sterile injecting practices. The Strathclyde/SED project will also result in specific curricular materials on AIDS, and the DES/Welsh Office AIDS video package has also been made available to education authorities in Scotland.

3.45 In Northern Ireland the Department of Education has recently issued a circular on sex education to schools as well as the guidance "AIDS: Some Questions and Answers". The Departments of Education and Health and Social Services are currently reviewing jointly the suitability of the DES/Welsh Office video for use in schools in Northern Ireland in its present form.

Recommendation 44

We believe that in-service training for those teaching sex education in general and AIDS in particular is vital.

3.46 In-service training clearly has an important role to play in ensuring that teachers have the necessary knowledge and skills to enable them to tackle teaching about AIDS authoritatively and with confidence. A range of in-service provision is already available in the sex education field, although it may form part of more broadly-based courses concerned with Personal and Social Education and Health

Education, rather than being identified separately. Some local education authorities are already offering training sessions on the subject of AIDS. Existing courses concerned with teaching about sexual behaviour and the risks of drug misuse are also likely now to refer to the AIDS dimension.

3.47 Much of the impetus for in-service training in relation to AIDS must rest at local level in response to the identified training needs of staff in the area. Training related to the misuse of drugs is a national priority area within the Local Education Authority Training Grants Scheme: grant is therefore available at the preferential 70 per cent rate on training related to AIDS in the context of drug misuse. It is open to any authority to designate AIDS-related training or training in sex education as a local priority under the scheme for which 50 per cent grant is payable from central government. The DES is considering the possibility of commissioning research to identify more precisely the training needs associated with AIDS education and to develop appropriate training materials. The DES/Welsh Office video package has been sent, for information, to all establishments in England and Wales providing courses of initial teacher training.

3.48 In relation to initial training, if courses are to obtain the approval of the Secretary of State for Education and Science, they must introduce students to the pastoral responsibilities of teachers and provide a basic understanding of the relationship between the adult world and what is taught in schools.

3.49 In Scotland in-service training in relation to drugs education is designated as a national priority area for which education authorities may receive specific grant at 75 per cent. The remit for the Strathclyde/SED project on health education and AIDS includes the consideration of teachers' in-service training needs.

Recommendation 46

We recommend that there should be adequate provision of health education information for those in full-time education after the age of 16. This will be a major challenge for the new Health Education Authority as well as for the DES.

3.50 The Committee recognised the difficulty of reaching those in full-time education after the age of 16 by formal means, given the organisation of educational provision at this level. The Government trusts that those within institutions with responsibility for determining course content will consider seriously how adequate provision may be made for health education. As the Committee also noted, the Government's factual booklet has been made available to lecturers in establishments of further and higher education. In addition, the National Union of Students (NUS) has issued guidance directly to students; its activities have been complemented by those of individual student unions and institutions. The Education Departments have circulated the Government's factual booklet to all of the unions affiliated to the NUS at the latter's suggestion. Collaboration between health and education bodies has already been established. The Youth and Community Service (the community education service in Scotland) has a part to play in combating the spread of AIDS: it is ideally placed to get in touch with young people, including those who might not read conventional pamphlets or newspapers. Copies of the DES/Welsh Office video package have been distributed, for information, to Principal Youth Officers in local education authorities and to General Secretaries of National Voluntary Youth organisations.

3.51 Young people in this age-group are of course open to the influence of the Government's Public Education Campaign, in which the young have been identified as a particular target audience: they are not dependent on the education system alone for information and advice about AIDS. The Health Education Authority's strategy for carrying forward the public education campaign includes a proposal to target the 16 to 25 age group. The Government recognises the need for continuing collaboration between the DES and the Authority in providing educational material on AIDS and sexual behaviour for young people including those in full-time education.

3.52 In Scotland Forth Valley Health Board has recently embarked on a joint initiative funded by SHEG to prepare a video resource package on AIDS for the 16+ age group especially targeted at less able school leavers, to be disseminated through

YTS and organisations catering for young offenders. The initial stages of this project involve Strathclyde University's Department of Marketing in surveying the needs of young people and pre-testing materials. It will be ready for dissemination in late summer. The SED has recently distributed a booklet entitled "Confronting AIDS" to students at central institutions and further education colleges, as well as to the community education service for the use of their participants. A training package is being prepared to assist further education lecturers and community education staff in tackling the problem of AIDS as it arises in their work. The modular courses used in further education colleges are being reviewed to ensure that suitable references to AIDS are made, for example in the context of personal and social development or health and safety at work.

*The Health
Education Authority*

Recommendation 48

The Health Education Authority is intended to take on the bulk of responsibility for the AIDS education campaign. We hope that the fact that the authority has been undergoing a major transformation at the outset of its new responsibility for AIDS will not hamper its work.

3.53 Overall responsibility for the development of future phases of the mass media elements of the AIDS public education campaign, and responsibility for other aspects of the campaign in England, were transferred to the Health Education Authority (HEA) in October 1987. The territorial health education agencies will be associated with the development of the mass media work and will continue to make their own distinctive contributions to meet the needs and circumstances of Scotland, Wales and Northern Ireland. The HEA and the DHSS have co-operated closely in the formulation of AIDS educational initiatives and the HEA has completed an outline strategy for the development of the campaign and operational programme for the remainder of the current financial year. The HEA's Operational Plan for 1988-89 has also been completed and submitted to the DHSS. The reconstitution of the Health Education Council as a special health authority has strengthened its capacity to carry forward its work on all fronts. A co-ordinating group has been established at which officials from interested Departments and the territorial health education agencies can discuss the development of the campaign with HEA staff. Local Health Education Units too will be kept in touch with developments related to the campaign, and the many consequences of HIV infection. The Government believes that messages targeted at drug misusers must continue to be developed in conjunction with the drug prevention campaign which is itself an important strand in the Government's strategy for tackling drug misuse. Responsibility for this work will remain with the Government for the remainder of the current financial year and the position will be reviewed in the light of the evaluation of the latest work. Whatever the outcome of this review, a drug prevention campaign will remain an integral part of the Government's strategy against drug misuse and retain a high priority.

*Stigma and the Role
of the Media*

Recommendation 85

We hope that the understanding of the disease and its problems which the education campaign is trying to bring about will remove the stigma attached to sufferers.

Recommendation 89

The media, and in particular television, have a major potential to assist in education, not only about the specifics of AIDS and HIV, but in promulgating responsible attitudes that respect personal freedom and rights while protecting the public health. These powerful forces in our society must be harnessed for the general good. This need not infringe their freedom, so long as the rights of the individual to privacy in matters of health are recognised as paramount.

3.54 The Government shares the Committee's view about the power of the mass media, and in particular television, in shaping attitudes and in the delivery of health education messages. In mounting its AIDS Education Campaign the Government has made extensive use of all mass media outlets, including the press, radio, television and the cinema. The Government sought the co-operation of the BBC and IBA in carrying the campaign forward and welcomed the boost given to it by the

AIDS Week on television at the end of February 1987, following the earlier radio AIDS week at the end of 1986. This was a unique co-operative initiative by all television channels.

3.55 One of the objectives of the public education campaign is to dispel myths and misconceptions which have arisen about transmission routes for HIV infection. It is most important that this should be done, no unrealistic public fears about transmission routes should threaten the caring and compassionate approach to people with AIDS or HIV infection that the Government wishes to foster. The Government shares the Committee's view about the need to respect the rights of individuals and endorses the Committee's view of the importance of the right of privacy in matters of health care.

Care and Treatment

4.1 The four-stage pattern of illness following HIV infection, which is described in paragraph 109 of the Committee's Report, reflects the general experience in this country to date. As the Committee stresses in the Report introduction, however, this is a rapidly changing and evolving situation. Work still needs to be done to clarify the particular health care and social support needs of people who have HIV infection, AIDS-related conditions, or AIDS, and how, in the latter case those needs may vary from diagnosis through to the terminal stage of illness. The effects of treatment with Retrovir on the course of the illness and the consequent pattern of demand for services have still to be evaluated. Care must be taken to construct a service response flexible enough to enable the re-deployment of resources as understanding of needs develops.

4.2 The Government's broad policy aims for health authorities have emphasised to date three main aims:

- prevention of the spread of HIV infection;
- provision of diagnostic and treatment facilities and counselling and support services; and
- promotion of better understanding of HIV infection.

Health authorities will be asked to continue to plan on that basis. In relation to the provision of services for people who have, or believe they may have, HIV infection or HIV-related illness, the Government's specific policy aims are:

- (a) provision of appropriate personal counselling and HIV antibody testing for people at risk of HIV infection who seek advice and of appropriate training in counselling skills for staff and volunteers involved;
- (b) provision of appropriate diagnostic follow-up services for all people found to have HIV infection;
- (c) provision of care and treatment in the community for people who have HIV-related illness and the effective co-ordination of hospital and community care;
- (d) provision of appropriate treatment facilities for people with HIV-related illness, including hospital out-patient and day patient services, acute and non-acute hospital beds, and beds available for terminally ill people who cannot be cared for in their own homes; and
- (e) provision of support and training for professional and informal carers of people with HIV-related illness, through collaboration between health and local authorities and the voluntary sector.

4.3 The health departments are developing specific service objectives for health authorities (health boards in Scotland) to achieve those aims. For authorities in England, a fundamental requirement is likely to be the agreement by each Regional Health Authority (RHA), in collaboration with its District Health Authorities, of a Regional strategy for the provision of services for people with AIDS or HIV infection.

4.4 Such a strategy will need to clarify the services which each District should plan to provide from within its available general resources, services which need to be

provided on a sub-Regional or Regional basis, patterns of referral to and the usage of such services, and services to be provided for or by health authorities in other Regions. District plans will need to be drawn up in consultation with the relevant local authorities and voluntary organisations. Each regional strategy will need to address the particular needs of separately identified groups of people (for example, homosexual and bisexual men, drug misusers, haemophiliacs and children who have HIV infection).

4.5 Linked with the development of services for the care and treatment of people with AIDS are public health measures to control the spread of HIV infection. The Government took early action in this field. All donations of blood since 1985 have been screened for HIV antibodies and donors of other organs and tissues are tested too. Blood products for haemophiliacs are screened and heat treated. Existing guidance on control of infection procedures is currently being revised by a sub-group of the Chief Medical Officers' Expert Advisory Group on AIDS. Regional strategies on AIDS will be expected to give details of the policies to be developed by health authorities on control of infection and for the treatment of people known to have AIDS or HIV infection.

4.6 To date, it has been the health authorities in London, Edinburgh and other major cities, which have had to cope with the main AIDS-related demands on diagnostic, counselling and treatment services. In London, the bulk of those demands has fallen on three authorities, Riverside, Bloomsbury and Paddington and North Kensington. The Government has responded by exceptionally making additional resources available for hospital and community health services.

4.7 In 1986-87 an additional £3 million was allocated to the NHS for AIDS services, the majority going to North West, North East and South East Thames RHAs for treatment and counselling services, in recognition of the disproportionate incidence of cases in those Regions. In 1987-88 a total of £22.5 million has been allocated to the same three Thames Regions. These funds are intended as a contribution to additional costs; they are not intended to cover all of the costs that may be attributed to the development of AIDS-related services. The DHSS has also allocated in 1987-88: £280,000 for haemophilia reference centres; £1 million for initiatives in drug misuse counselling; and some £800,000 for other AIDS-related projects.

4.8 The Government intends to put the planning and funding of AIDS-related services on a firm footing for the future. In England the Secretary of State for Social Services has earmarked £58.6 million in 1988-89 to help develop preventive counselling and diagnostic services and to make a contribution towards the costs of care and treatment in hospitals and in the community for those with AIDS or HIV infection. This money will be allocated between regions taking account of the reported number of people with AIDS whom they are treating. This level of central provision should make an important contribution towards the cost of AIDS-related services enabling health authorities to develop adequate services for people with AIDS and related conditions while maintaining other priority services. In Wales, planning guidelines have been published and district health authorities have prepared draft operational plans for dealing with AIDS. £140,000 has been made available this year for counselling and diagnostic services.

4.9 In Scotland, so far as service objectives are concerned, the Government set up an expert working party in November 1986 under the Chairmanship of the General Manager of Lothian Health Board to advise on the most appropriate and cost-effective methods of organising services for people with AIDS or HIV infection and to quantify the resource costs for the community health services and family practitioner services. The working party reported in May 1987, and following consultation with interested parties, the Government responded in July 1987. This response endorsed the working party's view that the imminent increase of people with AIDS in Scotland will require a complex yet co-ordinated set of services to ensure effective and humane care; but that AIDS must also be seen in the broader perspective of the health service and might require an alteration in strategic priorities within the NHS. The working party's report contains many recommendations which relate to the way in which facilities should be reviewed, provided, supplemented or

modified by Health Boards generally. The Government has commended these recommendations to the consideration of the Health Boards, and has asked Boards to take them into account in their strategic planning for HIV infection and AIDS, having regard to their particular circumstances.

4.10 The Government response fully endorsed the general approach to the treatment of people with AIDS or HIV infection recommended by the working party, and in particular endorsed the view that wherever possible a person with AIDS should be cared for in his or her own home among the family or with a spouse or partner. The Government also endorsed the working party's recommendation that three special AIDS Units should be set up in Edinburgh, Glasgow and Dundee as soon as possible, although the Government made it clear that these units should not preclude the admission of individual patients to general hospitals where appropriate. The Government has undertaken to make specific allocations to the three Boards concerned to meet the additional capital and revenue costs in the next three financial years of a 15-bedded special AIDS unit in each of Edinburgh and Glasgow and a 10-bedded unit in Dundee. So far as other resource implications of AIDS for the NHS in Scotland is concerned, the working party's report made it clear that, for 1988-89 and the forward years, the likely costs will in general remain very small in relation to individual Boards' allocations. In these circumstances, Boards have been asked to continue to accommodate the costs of services in connection with AIDS and HIV infection within their normal allocations, although there may be some scope for consideration of additional allocations if exceptional and unforeseen pressures in some areas of service provision arise. Boards have been asked to monitor costs carefully.

Counselling and Training

Recommendation 50.

We recommend that GPs and all other members of primary health care teams are trained, not only in the facts of the disease, but also in counselling skills.

Recommendation 51.

The importance of counselling in the care of a person with HIV infection or disease demonstrates the need for more fully trained counsellors. Without them we cannot hope to manage patients. The provision of training must be resolved at once in co-ordination with the voluntary bodies working in the field.

Recommendation 60.

We recommend a programme of training about HIV and AIDS for all relevant local authority workers.

Recommendation 61.

A much more extensive programme of education is needed for all members of Primary Health Care teams.

Recommendation 62.

The educators must be educated.

4.11 To assist efforts being made by health authorities to train staff in necessary counselling skills, the Government has funded centrally training courses at Paddington and North Kensington, Bolton and East Birmingham Health Authorities. In 1987-88 £200,000 has been allocated centrally for the development and provision of such courses.

4.12 Central funds have also been allocated for a course for general practitioners in the Clinical Management of AIDS Patients, which is being run at St. Stephen's Hospital, London. General practitioners' participation on the course will be on a priority basis related to the prevalence of AIDS in their area. Part-time appointments in three London Hospitals have been funded for general practitioners to care for people with AIDS under the supervision of hospital specialists. Similarly the Government has funded regional workshops for senior community nurses; and has awarded thirteen AIDS Fellowships worth £3,000 each and funded the English National Board for educational initiatives, for nurses, midwives and health visitors. A similar fellowship is being awarded in Wales.

4.13 In addition the Government looks to the relevant professional bodies, health authorities and Family Practitioner Committees to take forward training of general practitioners and other health care professionals in agreement with professional staff locally. The DHSS has drawn attention to the need for adequate provision to be made by each District for the training of counsellors and volunteers to work with people with AIDS or HIV infection in its checklist of items for District Health Authorities to cover in their AIDS action plans, which was issued in May 1986. In Scotland, the Scottish Council for Post Graduate Medical Education is devising a distance learning programme on AIDS for distribution to general practitioners, and is advising on the need for updated education on the topic for all medical staff. The Scottish Health Education Group is preparing a training pack for general practitioners on the health education aspects of AIDS. The Group also has a series of initiatives in hand on training and counselling: these include modular courses on counselling and helping skills, a directory of counselling services and training, and the preparation of guidance for counselling trainers.

4.14 Local authority staff including social workers are able to attend the counselling training courses mentioned above. The development of specific programmes of training for particular groups of staff for the professional training bodies and for local authorities as employers to take forward individually or through their representative associations. The relevant Government Departments will keep in touch with the local authority associations' working party on AIDS on this and other issues.

Recommendation 77.

We know that we need more counsellors, more fully-trained, and a more co-ordinated system of support and supervision, but we are not certain how this should be achieved. We recommend that the Secretary of State carefully re-examine the whole issue of counselling provision, in particular to provide in-depth support for professional, voluntary and informal carers.

4.15 The DHSS is considering the future planning and funding of courses for counsellors in the field of AIDS and HIV infection. It will consider in particular the needs for support of formal and informal carers, and how these can be met.

Patterns of Care

Recommendation 55.

For our part, we incline towards seeing treatment by a team, led by a designated physician as being most appropriate.

Recommendation 56.

We accept the arguments for regional centres of advice and referral, which should be designated without delay by health authorities. Hospital services should be funded in the widest sense, rather than just via an AIDS ward. This means the provision of properly trained medical, nursing and paramedical staff with a full and expanded range of support services, including pathology and radiology. [In addition, designated facilities for the safe performance of autopsies are required in all regions]*.

4.16 The management and organisation of patient services is for consideration at Regional and local level by health authority managers in consultation with their professional staff. The DHSS has established a working group to consider the implications of AIDS for the NHS, on which health service managers, clinicians and social service providers are represented. It will be considering what guidance can be given on appropriate patterns of care, including the possible need for designated regional centres of advice and referral. The Government, in guidance sent to Regional General Managers in May 1986, has already requested that one or more appropriately trained physician in each acute hospital should be designated to take a special interest in and concern for the treatment of full clinical AIDS cases.

(*the final part of this recommendation is dealt with in paragraph 4.22 below).

Recommendation 63

In our earlier Report on Community Care for mentally ill and mentally handicapped people, we said: “The stage has now been reached where the rhetoric of community care has to be matched by action”. We reiterate that statement with still greater force.

Recommendation 64

If we get community and primary care right in respect of AIDS, there is no reason why we should not get it right across the board.

Recommendation 65

We recommend that local authorities and health authorities at all levels establish joint planning procedures and designate a member of staff to act as AIDS liaison officer to co-ordinate their work.

4.17 The then Secretary of State for Social Services, at a conference which the Government held in March 1987, stressed the importance of community care of people with AIDS or HIV infection. The Government agrees that this requires close co-operation between local authorities and voluntary agencies but it does not wish to be prescriptive about the mechanisms to be adopted for securing such collaboration. That is a matter for health and local authorities to determine locally in the light of their particular circumstances both as regards the development of AIDS cases and the form of existing services. The designation of an AIDS Liaison Officer to co-ordinate joint planning is consistent with the guidance issued in May 1986 that the nominated community physician in each District should establish liaison with the local authorities under the Family Practitioner Committee on AIDS-related issues. The DHSS working group on the implications for the NHS of AIDS will look at the issue of collaboration when considering possible guidance on patterns of care. The broader question raised about the effectiveness of care in the community is a subject of consideration by the inquiry currently being carried out by Sir Roy Griffiths. This report is expected shortly.

Recommendation 71

We underline the need for respite and convalescent care, including some sheltered housing, for patients with AIDS and ARC.

Recommendation 73

Given the manpower, we see few obstacles to extending the essence of the hospice into the community. We recommend that DHSS consider the extent to which training facilities offered by St Christopher's and other hospices already benefit the NHS and their potential for developing services for the terminally ill.

4.18 The DHSS is considering how best to obtain up to date information on the needs of people with AIDS for continuing and terminal care and sheltered accommodation, their need for respite care facilities to help friends and relatives who look after them, and how these are being met. It should not be assumed that all who have AIDS will have the same needs or that responses developed in, for example, London, will necessarily be appropriate for people with AIDS in other parts of the country. The hospice movement has made a positive response to the challenge of AIDS. Help the Hospices held a conference on the topic in October 1987 at which the willingness of many hospices to help care for people with AIDS and to offer training in terminal care to NHS staff working in hospital and in the community was reaffirmed. The Government welcomes this sharing of knowledge and resources and will do all it can to encourage it.

Recommendation 74

Nurse practitioners will be an invaluable asset to the community nursing team.

4.19 Community nursing is addressed in the Government's White Paper on Primary Health Care. Evidence submitted to the Government's review of primary care showed a good deal of support for the introduction of nurse practitioners. The Government welcomes the interest shown in the concept of a nurse practitioner and intends to look further, in consultation with the professional interests concerned, at such issues as legal status, functions and qualifications. However the Government has indicated (DHSS circular HC(87)29) that it would hope to see some early steps that make better use of the talents and skills of all nurses working in the community. This could include providing patients with a source of initial advice in the practice team other than from a doctor.

Recommendation 75

London Lighthouse's planning and organisation has been impressive. They have pioneered a facility which could provide a model for such projects elsewhere, and which will save the NHS a great deal of money, but which above all will provide the type of care that people with AIDS actually want. In recognition of this, and to give the lead which we think is needed to galvanise the charities into action, we recommend that the Secretary of State demonstrate his support for the Lighthouse Project by matching their fund-raising as they request.

4.20 The Government has approved a capital grant of £500,000 in 1987-8 towards the costs of converting London Lighthouse's premises, and a revenue grant of £100,000. The Government is considering their request for further assistance. Officials are in discussion about their proposed operational policies, the links they have established with the health and local authorities in their locality, and the organisation's capital and operational budgets, and how the running costs will be met. The Government hopes to respond shortly.

Recommendation 76

Like the hospice, the principles upon which San Francisco's programme is based can be translated anywhere.

Recommendation 81

We hope that the pattern of care which develops will be sufficiently flexible to care for all people with AIDS or HIV infection, regardless of age, sex or past medical history.

4.21 There is much to be learnt from the principles upon which the San Francisco programme of care for people with AIDS is based, and the Government has sought to do so through visits to that city. The Director of the AIDS Office of the San Francisco Health Department, Dr George Rutherford came to address the Government's conference on Caring for People with AIDS in the Community, in March 1987. However, application of the principles needs to take account of local circumstances and needs, and there are reasons for thinking that they could not readily be applied to drug misusers or people who are homeless. The American Institute of Medicine have expressed doubts as to whether the model can be replicated elsewhere in the United States. The Government shares the Committee's hope, however, that the pattern of care will be sufficiently flexible to meet the needs of all patients.

Control of Infection

Recommendation 56

[We accept the arguments for regional centres of advice and referral, which should be designated without delay by health authorities. Hospital services should be funded in the widest sense, rather than just via an AIDS ward. This means the provision of properly trained medical, nursing and paramedical staff with a full and expanded range of support services, including pathology and radiology.]* **In addition, designated facilities for the safe performance of autopsies are required in all regions.**

(*the first part of this recommendation is dealt with in paragraph 4.16 above).

4.22 The safe performance of autopsies can be secured by observance of the correct procedures; specially designed facilities for infectious diseases are not required. The Howie Code of Practice indicates the precautions which must be taken with all autopsies to avoid possible transmission of infection. A revision of these guidelines is presently under way under the auspices of the Health Services Advisory Committee. An autopsy should not be undertaken on a person who has died of AIDS unless absolutely necessary to make a diagnosis and should be performed only by a consultant pathologist with the assistance of experienced anatomical pathology technicians (as indicated in the Advisory Committee on Dangerous Pathogens revised guidelines for LAV/HTLV III of June 1986).

Recommendation 58

We recommend a more consistent approach to infection control policies and their application and we look to local authority environmental health officers to achieve this.

4.23 Policies for control of infection call for effective collaboration between health and local authorities. How this can be encouraged and facilitated is among the matters being considered by the inquiry into the public health function chaired by the Chief Medical Officer of the DHSS which is currently in progress and which is expected to report shortly.

Recommendation 57

There is a professional duty to reassure, and all health care professionals should adopt and practice appropriate and consistent procedures for infection control in health care practice as soon as possible.

Recommendation 59

We recommend that employers and employees and their representatives review health and safety practices to ensure that they meet the required standard, and that the reasons for the procedures be explained as part of a worker's basic training.

4.24 The Department of Employment and the Health and Safety Executive's booklet "AIDS and Employment", and also the Advisory Committee on Dangerous Pathogens' revised guidelines, set out the Government's position in respect of health and safety. Equivalent guidance on AIDS and employment has been issued by the Department of Economic Development in Northern Ireland. These support the Committee's recommendations. In addition a sub-group of the Chief Medical Officers' Expert Advisory Group on AIDS is urgently reviewing the position and considering the need for further guidance to health service managers and health care workers on the prevention of HIV transmission in health care settings.

Recommendation 78

We commend the way in which the Blood Transfusion Service has responded to the challenge of AIDS, protecting donor and recipient alike, and urge a constant review of policy and procedures to maintain that high standard.

Recommendation 79

We are pleased that guidelines are being devised for autologous blood transfusions, which will recognise both the value and the limitations of the idea.

4.25 The Blood Transfusion Service is constantly reviewing its policy and procedures in order to maintain the safety of the blood supply. Publicity to discourage the donation of blood by those most at risk of HIV infection is regularly updated to maintain its impact. The continued effectiveness of the HIV antibody tests used on all donations is monitored on a systematic basis to ensure that a high level of quality and reliability is maintained.

4.26 Guidelines to doctors for autologous transfusion have now been prepared by Regional Transfusion Directors and have been circulated to haematologists.

Resources

Recommendation 49

We recommend that the Secretary of State ensure that district health authorities allocate sufficient resources to GUM clinics and where appropriate additional facilities for drug misusers.

4.27 The DHSS is following up the letters sent to Health Authority Chairmen by the then Secretary of State in December 1986, by setting up a small enquiry team to examine pressures on GUM Clinics. Its terms of reference are to examine current and forecast workloads on GUM Clinics taking account of AIDS and other sexually transmitted diseases and to recommend any action which may need to be taken on manpower (including nursing manpower), training, resources and accommodation. As described above (paragraph 3.26), health authorities have been asked to give priority to services for drug misusers and additional funds have been provided for this purpose.

Recommendation 52

We believe that, with large numbers of people developing an illness which requires intensive levels of care and a high level of expertise for its proper management and which affects a sector of the population who would not otherwise have placed any demands on the health services, additional manpower provision is urgently needed in both training and consultant grades in traditional specialties and in the specifically relevant specialties of clinical immunology and infectious diseases.

Recommendation 54

The health service must be viewed nationally as well as regionally. We recommend that the NHS management board ensure that there are properly trained staff in all specialties. If a need is perceived, it should be met. It is not enough to hope that the various individuals around the country will act in the interest of all, at the behest of the Secretary of State. A much more active approach on the part of the Department itself may be required to fulfil requirements. If so, that is a necessary, if possibly unpleasant, fact of life and management.

4.28 The Government accepts that AIDS will add to the workload of medical staff in many specialties and that urgent assessment of additional staffing requirements is needed. At consultant level, the responsibility for this lies with Regional Health Authorities. As for training posts, the Government ensures, through bodies such as the Joint Planning Advisory Committee, that the number of training posts (in the case of the JPAC senior registrar posts) balances the likely consultant vacancies in each specialty. RHAs and the Royal Colleges have been asked to consider what the demands for new consultant posts are likely to be in the light of experience of AIDS, and the JPAC will then ensure that there are enough training posts in the relevant specialties to meet this demand.

Recommendation 53

We recommend that steps be taken to strengthen the NHS parasitology unit to enable it to undertake in-service training necessary to make parasitology expertise more widely available in the NHS and at the same time cope with its increased workload consequent on the AIDS epidemic.

4.29 The standard of parasitology diagnosis in the NHS has been under consideration by the DHSS following a pilot survey on the quality of parasitology diagnosis. Most medical and non-medical microbiologists receive some training in parasitology and update courses have been held in at least one of the London Colleges which Medical Laboratory Scientific Officers attend for training. The microbiology national external quality assurance scheme now incorporates a special sub-scheme

for parasitology for which the take-up has been good. This should help strengthen parasitology work. Some in-service training is already conducted at the London Hospital for Tropical Diseases, which has a parasitology department.

4.30 The Liverpool School of Tropical Medicine and Hygiene and the London School of Tropical Medicine and Hygiene also have departments of parasitology. To a lesser extent the Nuffield Department of Medicine at Oxford, Birmingham and other university departments also have interests in tropical medicine and parasitological diseases.

Recommendation 66

We are not in a position to dictate how caring for AIDS should be funded at local level. We suspect that it will involve a combination of general funding of health and social services and particular grants for those aspects which are specific to AIDS. Joint funding is inevitable; therefore it should be encouraged and facilitated at national as well as local level. Since we need a community care programme, we must be prepared to pay for it and we should not rule out specific grants.

Recommendation 67

Whatever is decided on how the services are to be funded and who will fund them (and this must be done without delay) there is dire need for some emergency funding to cope with the problem as it exists.

Recommendation 68

The fears of “trade off” and “backlash” are very real: they must never be realised. No other area should suffer as a consequence of funding research and care of AIDS.

Recommendation 69

In all the areas we have covered in this report, we have identified a need for more money, more manpower, more facilities, more resources of all kinds. These require injections of money as specific points, each request judged on its own merits and, if justified given the funding it requires. It is not good enough for the Government to respond to criticism by saying “we have given something”; effective delivery of patient care will require a continuing financial commitment.

Recommendation 70

We believe that a strategic response is needed which must plan for the next 5 to 10 years. The Government has to judge the level of need and respond appropriately. If they overestimate, the potential is there to redirect resources where they are needed. If they underestimate, they may endanger the concept of proper care for all.

Recommendation 94

Obviously the Government has the lead role to play in responding to the challenge of AIDS — and we are encouraged by its initial response. However even in these early days of the disease, we received evidence of under-resourcing which disturbed us and to which we have drawn attention. If the current estimates of the likely spread of the disease are in any way accurate, then the demand on resources will increase substantially and rapidly. In our view this rising demand must be met from new resources and not by diverting resources from other parts of the NHS or of the social services.

4.31 These recommendations relate to issues covered in the introduction to this part of the Response. The NHS faces ever increasing demands on its services which place pressure on the resources allocated to it within the Government’s public

expenditure plans. By its character, potential size and rapid growth, the spread of HIV infection takes on a special significance. In determining what proportion of the overall public expenditure programmes should be devoted to the Health and Personal Social Services, the Government will have regard to the significant resource implications of AIDS, as well as to other necessary service developments and priorities. For 1987–88 provision for the hospital and community health services in England was increased by £633 million. Additionally £262 million was provided to meet the costs of the Review Body Awards, £6.5 million for AIDS and a further £75 million to health authority cash limits to relieve the shortfall in income that could otherwise only have been eliminated by short-term measures which would not have improved health care or efficiency. Health authorities also have the benefit of savings, released through their cost improvement programmes, which are expected to yield some £150 million in 1987–88. In 1987–88 health authorities have received cash increases of 9.1 per cent (4.7 per cent in real terms).

4.32 The Government's policy is to allocate funds to RHAs (who in turn make allocations to Districts) and to leave it to each authority how those funds should be spent. As the general allocation of health authority funds, using the RAWP formula, takes no account of the geographical distribution of people with AIDS, the Government has exceptionally in 1986–87 and again in 1987–88, made additional specific allocations (see paragraph 4.7).

4.33 It is important that available resources are directed to those areas of the country and those parts of the NHS carrying the greatest burden. The Government recognises also the increased pressures on personal social services departments in particular areas, and is considering how they may be helped. Some recognition in the general rate support grant arrangements of the additional work arising from AIDS, which affects all local authorities to a greater or lesser extent, may be appropriate, but there are major differences between local authorities in terms of their current involvement with people with AIDS. The Government, therefore, is considering how funds might be specifically targeted. For 1988–89 £2 million will be provided out of £58.6 million extra funds for AIDS-related services, for allocation to selected inner London boroughs that face the greatest immediate pressures, under joint finance arrangements. For the longer term there is the possibility of a specific grant being made to certain local authorities. That would require legislation and is something which needs to be discussed with local authorities.

4.34 It is still for health and local authorities, however, to plan services and allocate their resources according to local plans, priorities and circumstances, within a broad framework of guidance on national and regional priorities and objectives. Priority of access to treatment services is determined by individual doctors according to the clinical needs of patients requiring treatment. The Government sees no reason to disturb those arrangements which will equally serve the competing demands of AIDS patients and all others who look to the NHS to meet their needs.

4.35 It would not be practicable to identify separately for resource allocation purposes all treatment and care services provided for people with AIDS, since they are mainly of a kind already available to patients who suffer from other conditions. Nor is it realistic to assume that AIDS-related services or research can, or should be given absolute priority over all other health or Government spending; nor protected from the pressures and constraints that other health and personal social services experience. In short, there can be no question of blank cheque funding, as the Committee itself acknowledges.

4.36 In Scotland, the working party under the General Manager of Lothian Health Board (see paragraph 4.9) concluded that it would not be appropriate, in the Scottish context, to make forecasts of numbers of people with AIDS or recommendations beyond the year 1991, but Health Boards will roll forward their plans for future years and, as experience increases, it may be possible to set the planning horizon further ahead.

Recommendation 80

We recommend that all haemophilia centres have the requisite funding to enable them to cope with the extra work AIDS and HIV entails for them. Ideally, this

money should include specific provision for a fully trained AIDS counselling service.

4.37 The care of haemophiliacs with HIV infection is well established. The Government has given £650,000 to haemophilia centres since September 1985 for HIV counselling of haemophiliacs and their families. Counsellors at haemophilia centres have been trained and the Haemophilia Centre Directors have organised two seminars to discuss the problems of counselling.

4.38 The main demand for counselling haemophiliacs derived from their use of infected non heat-treated Factor VIII. This is now treated to inactivate HIV and new cases of infection are not arising. Further expansion of counselling facilities for haemophiliacs is not, therefore, considered necessary.

4.39 The Government has recognised the unique position of haemophiliacs with HIV infection, and that their circumstances are wholly exceptional. It has decided that an ex-gratia grant of £10 million will be made to the Haemophilia Society. This is not compensation but is to enable the Society to establish a special trust fund to make payments to affected individuals and families throughout the United Kingdom.

Wider repercussions *Worst projections*

Recommendation 82

In the worst possible projections, we could face an escalating drain on the resources of the NHS and the diminishing capability of the economy to pay for it.

5.1 The Committee's observation about the worst possible projections are noted but there is no evidence to suggest such projections are likely. The objective of the Government's public education and infection control measures is to ensure that the spread of HIV infection is minimised.

Employment

Recommendation 83

We can see the benefits of permitting advocacy or tribunals in camera in unfair dismissal hearings involving people dismissed as a result of being infected with HIV. We suggest a review of the qualifying time period for entitlement to statutory rights against dismissal in these cases.

Recommendation 84

There is no reason why a test for HIV should be included as part of a medical examination required by an employer, unless it can be proved that the infection or illness will directly affect job performance.

5.2 The rules of procedure for industrial tribunals already make provision for certain cases to be heard in private, but the limited circumstances in which this may happen would not include people dismissed on account of AIDS. As to this and the suggestion that the qualifying period (currently two years) for entitlement to statutory rights against dismissal should be reviewed in respect of AIDS and HIV cases, the Government does not consider that they should be treated any differently from other cases of unfair dismissal.

5.3 The Government agrees with the Committee that HIV tests in relation to employment can be justified only if it can be proved that HIV infection will directly affect job performance. The majority of people with HIV infection who are at work are completely well and they and their employers will be unaware that they are infected. There is no indication that infection with HIV should be treated differently from any other infection or illness. This is the general message in the joint Department of Employment and Health and Safety Executive booklet "AIDS and Employment" published in November 1986, of which over three million copies have been distributed.

5.4 The position of health care workers with HIV infection is being urgently considered by the Chief Medical Officers' Expert Advisory Group on AIDS sub-group referred to above (see paragraph 4.24). It is hoped to issue guidance to

health service managers and health care workers on this matter shortly. In addition the General Medical Council issued a statement on 27 November 1987 in which they placed a duty on doctors who considered that they may have been infected with HIV, to come forward for appropriate diagnostic testing and counselling and to follow advice they receive from counselling.

Confidentiality

Recommendation 88

There are no grounds for disclosing a patient's antibody status without their consent, except to safeguard another from infection.

5.5 The Government shares the Committee's view about the importance of maintaining the medical confidentiality of HIV infection. The NHS (Venereal Diseases) Regulations 1974 oblige the health service to keep confidential all information capable of identifying an individual with a sexually transmitted disease. Under these Regulations confidential information may be disclosed only for the purpose of the prevention of spread of the disease or its treatment, and disclosure is restricted to people concerned with these tasks under medical direction. This applies not just to GUM clinics, as the Committee points out in paragraph 174 of the Report, but to health authorities themselves. In addition, the Department's advice on confidentiality in relation to AIDS reminds doctors of the existing principles for medical confidentiality in relation to personal health data. More generally, the health professions are subject to a code of professional conduct which, amongst other things, requires members of the professions concerned to keep all information learned from patients confidential.

Notification

Recommendation 86

Given present scientific knowledge, we do not see any reason to make AIDS a notifiable disease.

5.6 The Government shares the Committee's view that, on the basis of present scientific knowledge, there is no reason to make AIDS a notifiable disease.

International Travellers

Recommendation 87

We do not think that screening international travellers would be practical.

5.7 The Government agrees with the Committee that screening international travellers, including students, to the UK would not be practical. Nor does it think it would have any significant effect in reducing the spread of HIV infection in this country. It therefore sees no case in present circumstances for such screening, and as the then Secretary of State for Social Services said in evidence to the Committee, the Government has no plans to introduce screening for travellers to the UK. The Government notes that the WHO and the EC Health Ministers have taken the same view. Nonetheless, the Government understands that a number of other countries may be taking measures in this area, and it will be keeping the position under review.

Long-term Co-ordinating Body

Recommendation 91

We need a long term, strategically-planned response to AIDS. This response cannot come from one area or body alone. We recommend that a central long-term co-ordinating body be established, consisting of representatives of the different statutory bodies concerned, and including a representative of the National AIDS Trust to ensure co-ordination with the work of the voluntary sector.

5.8 The Government agrees with the Committee on the need for a long-term, strategically planned response to AIDS. Controlling the spread of HIV infection and providing appropriate help for those who are infected and who develop HIV-related illness requires such a response, the elements of which are set out in paragraphs 1.2 and 1.6 of this reply.

5.9 Responsibility for planning and carrying out measures to implement the strategy rests with a number of statutory bodies. The action required, particularly in a field where new services are being set up and developed, must reflect differences in local circumstances and may therefore vary in different parts of the country. The Government will be closely monitoring the effectiveness of the action taken.

5.10 As the Committee notes, arrangements for co-ordination have been established at Ministerial level. Arrangements have also been set up for exchanging information about HIV infection and its implications and for co-ordinating efforts within the statutory sector. Close links also exist between the Government and statutory agencies on the one hand, and voluntary agencies on the other. These arrangements are working effectively and the Government does not consider that a central co-ordinating body, as proposed by the Committee is needed. Arrangements for co-ordination and planning will, however, be kept under review and developed as necessary as the situation progresses.

Parliamentary Debates

Recommendation 93

We recommend that the Secretary of State for Social Services follows the precedent set on 21 November 1986 by initiating regular debates about the Government's AIDS strategy.

5.11 The Government welcomes the wide and informed interest in AIDS expressed in both Houses. It will bear in mind the Committee's view so that it can initiate debates on its AIDS Strategy, or other AIDS issues, as needs arise.





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